

# **HEALTH COMMITTEE**

Tuesday 13 September 2005

Session 2

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# **HEALTH COMMITTEE**

## **21<sup>st</sup> Meeting 2005, Session 2**

### **CONVENER**

\*Roseanna Cunningham (Perth) (SNP)

### **DEPUTY CONVENER**

\*Janis Hughes (Glasgow Rutherglen) (Lab)

### **COMMITTEE MEMBERS**

Helen Eadie (Dunfermline East) (Lab)

\*Kate Maclean (Dundee West) (Lab)

Mr Duncan McNeil (Greenock and Inverclyde) (Lab)

\*Mrs Nanette Milne (North East Scotland) (Con)

\*Shona Robison (Dundee East) (SNP)

\*Mike Rumbles (West Aberdeenshire and Kincardine) (LD)

\*Dr Jean Turner (Strathkelvin and Bearsden) (Ind)

### **COMMITTEE SUBSTITUTES**

Paul Martin (Glasgow Springburn) (Lab)

\*Mr Kenneth Macintosh (Eastwood) (Lab)

Mary Scanlon (Highlands and Islands) (Con)

\*attended

### **THE FOLLOWING ALSO ATTENDED:**

Lewis Macdonald (Deputy Minister for Health and Community Care)

Fiona Tyrrell (Scottish Executive Health Department)

### **THE FOLLOWING GAVE EVIDENCE:**

Dr Oliver Blatchford (NHS Argyll and Clyde)

Professor Anthony Busuttil (Law Society of Scotland)

Lesley Logan (Scottish Transplant Co-ordinators Network)

Murdoch MacTaggart (Procurators Fiscal Society)

Dr Calum MacKellar (Scottish Council on Human Bioethics)

Dr Jeremy Metters (Her Majesty's Inspector of Anatomy for Scotland)

Dr Elizabeth Robertson (NHS Grampian)

Dr Jim Rodger (Medical and Dental Defence Union of Scotland)

Mr Chris Rudge (UK Transplant)

Jan Warner (NHS Quality Improvement Scotland)

### **CLERK TO THE COMMITTEE**

Simon Watkins

### **SENIOR ASSISTANT CLERK**

Tracey White

### **ASSISTANT CLERK**

Roz Wheeler

### **LOCATION**

Committee Room 1

## Scottish Parliament

### Health Committee

*Tuesday 13 September 2005*

[THE CONVENER *opened the meeting at 14:00*]

### Item in Private

**The Convener (Roseanna Cunningham):** I welcome everybody to this afternoon's Health Committee meeting. I have apologies from Helen Eadie; Kenneth Macintosh is the Labour committee substitute and he will attend in her place. Duncan McNeil has also tendered apologies. Shona Robison is running late and will appear shortly.

Item 1 is consideration of an item in private. Members will recall that the unusual timing of last week's meeting meant that today's agenda had to be circulated before that meeting. Last week, the committee agreed to review in private the evidence that it hears on the Human Tissue (Scotland) Bill after each oral evidence session, so I remind members that item 5 will be taken in private, in accordance with last week's agreement.

## Subordinate Legislation

**Mental Health (Definition of Specified Person: Correspondence) (Scotland) Regulations 2005 (draft)**

**Mental Health (Absconding by mentally disordered offenders) (Scotland) Regulations 2005 (draft)**

**Mental Health (Use of Telephones) (Scotland) Regulations 2005 (draft)**

**Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Enactments) Order 2005 (draft)**

**Mental Health (Safety and Security) (Scotland) Regulations 2005 (draft)**

**Mental Health (Cross-border transfer: patients subject to detention requirement or otherwise in hospital) (Scotland) Regulations 2005 (draft)**

14:01

**The Convener:** We move on to subordinate legislation. The committee is asked to consider six affirmative instruments that all relate to the Mental Health (Care and Treatment) (Scotland) Act 2003. As they deal with a range of provisions that the act makes, dealing with them en bloc would be inappropriate. However, I suggest that we should discuss the instruments together, rather than one by one, after which I will ask the minister to move the motions separately. The Subordinate Legislation Committee has considered them and made no comment.

Agenda item 3 deals with negative instruments that relate to the 2003 act. The minister will make an opening statement about the affirmative instruments, and I ask him to say something about the negative instruments. I understand that that would be acceptable.

I welcome the Deputy Minister for Health and Community Care, Lewis Macdonald, who is accompanied by several officials—Fiona Tyrrell and Mike Murray from the mental health legislation team; Edythe Murie and Shirley Ferguson from the office of the solicitor to the Scottish Executive; and Geoff Huggins, who is the head of the mental health division and whose name was not notified to us in time to appear on the agenda. I ask the minister to make an opening statement, after which we will deal with the motions.

**The Deputy Minister for Health and Community Care (Lewis Macdonald):** I will set all the instruments in the wider framework of implementation of the 2003 act, with which many members are familiar. Members will be aware that the act comes into force on 5 October. We and others have undertaken considerable work to ensure that we are ready for that time.

First, completion of the legislative framework is required. That is really what we are about today. We have introduced many regulations following further consultation with those who have an interest. Many of those regulations provide more detail on how some provisions of the act should operate in practice.

The 2003 act provided for a limited number of regulations to be made under the affirmative procedure, such as those that appear on the agenda today. In general, they will make new provisions on specific matters, such as the cross-border transfer of patients. Those provisions have been the subject of consultation with users, carers and other interested parties.

As the convener said, several instruments that are subject to negative resolution are still to come, including the rules of procedure for the new mental health tribunal.

As required by the 2003 act, I have laid the code of practice in draft before the Parliament. The code has been the subject of considerable consultation and I hope that the final code of practice will be useful to people who perform duties under the act. For technical reasons that relate to the drafting of the Mental Health (Care and Treatment) (Scotland) Act 2003 (Code of Practice) Order 2005 (SSI 2005/417), my officials advise me that it may be necessary to produce another version of the order. That will not affect the content of the code of practice and is only a technical point, but the committee may wish to be aware of it, as the committee may consider that order in due course.

To raise awareness among service users and others, we have produced several guides on various topics that relate to the act, such as the advance statement.

The new mental health tribunal will come into being on 5 October. We have appointed a president to the tribunal and about 300 members. The tribunal's administrative staff are in the final stages of preparation for receiving applications and holding hearings.

We asked people in local areas to work together to develop and implement plans to improve mental health services and promote training for their staff in anticipation of the act coming into force. I am pleased to report that the reports that I receive show that significant progress is being made.

I will comment on the specific content of some of the regulations that are before the committee. The provisions in the regulations are supplementary, incidental and consequential in the usual way.

The draft Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Enactments) Order 2005 makes some minor drafting improvements to the 2003 act and amends references in other Scottish legislation and in United Kingdom legislation as it applies to Scotland to the Mental Health (Scotland) Act 1984, which will be repealed on the implementation of the 2003 act and is referred to in many pieces of legislation.

The draft Mental Health (Cross-border transfer: patients subject to detention requirement or otherwise in hospital) (Scotland) Regulations 2005 relate to detained patients who are to be transferred to a hospital in another part of the UK. They make provision for any patient who is receiving care and treatment in hospital for mental disorder to be transferred outwith the UK when that is appropriate.

Several other regulations are before the committee. Convener, would it be convenient for me to stop there and come back to address specific questions on specific regulations when we reach them?

**The Convener:** That would be useful. Thank you.

I have a couple of questions. Several of the instruments state that consultation has taken place through various means—both published consultation and informal consultation. Obviously, the legislation impacts most on those who are mentally ill. How have you ensured that the views and concerns of the mentally ill are represented in those consultations?

**Lewis Macdonald:** That has certainly been part of the process. Fiona Tyrrell or Geoff Huggins might like to comment on the detail of the consultation process.

**Fiona Tyrrell (Scottish Executive Health Department):** The public consultation went out to a number of professional and service groups and to groups that we know support service users, such as the Scottish Association for Mental Health and the National Schizophrenia Fellowship Scotland. We also have a Mental Health (Care and Treatment) (Scotland) Act 2003 reference group, which includes not only representatives of organisations that have an interest in service users and carers, but some service users and carers themselves, including a service user with learning disabilities. We therefore feel that we have gone directly to service users and carers and have heard their concerns about and aspirations for the 2003 act.

**The Convener:** You are satisfied that their views have all been taken into account.

**Fiona Tyrrell:** Yes.

**The Convener:** With regard to the draft order on the modification of enactments, the minister stated in a letter to the committee that the 2003 act makes amendments to the Regulation of Care (Scotland) Act 2001, which he states the Executive

“no longer wish to bring into effect in October as planned”.

Can you elaborate on that for the committee, particularly given our current interest in the 2001 legislation?

**Fiona Tyrrell:** The 2003 act removed from the Regulation of Care (Scotland) Act 2001 a definition of private psychiatric hospitals, but when we considered the issue further we decided that we wanted to retain the definition. We are not amending the 2001 act, so we are taking out the provision that would have amended it.

**The Convener:** Does any member wish to seek further clarification from the deputy minister or his officials with regard to any of the instruments?

**Members indicated disagreement.**

**The Convener:** Does any member wish to debate any of the instruments?

**Members indicated disagreement.**

**The Convener:** We move on to deal with the individual instruments. As I said at the outset, it would not be appropriate to deal with them en bloc. I invite the minister to move motion S2M-3178.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Definition of Specified Person: Correspondence) (Scotland) Regulations 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

**The Convener:** I invite the minister to move motion S2M-3183.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Absconding by Mentally Disordered Offenders) (Scotland) Regulations 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

**The Convener:** I invite the minister to move motion S2M-3184.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Use of Telephones) (Scotland) Regulations 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

**The Convener:** I invite the minister to move motion S2M-3208.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Enactments) Order 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

**The Convener:** I invite the minister to move motion S2M-3209.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Safety and Security) (Scotland) Regulations 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

**The Convener:** I invite the minister to move motion S2M-3210.

*Motion moved,*

That the Health Committee recommends that the draft Mental Health (Cross-border transfer: patients subject to detention requirement or otherwise in hospital) (Scotland) Regulations 2005 be approved.—[*Lewis Macdonald.*]

*Motion agreed to.*

### **Mental Health (Compulsion orders—documents and reports to be submitted to the Tribunal) (Scotland) Regulations 2005 (SSI 2005/365)**

### **Mental Health (Compulsory treatment orders—documents and reports to be submitted to the Tribunal) (Scotland) Regulations 2005 (SSI 2005/366)**

### **Mental Health (Conflict of Interest) (Scotland) (No 2) Regulations 2005 (SSI 2005/380)**

### **Mental Health (Removal Order) (Scotland) Regulations 2005 (SSI 2005/381)**

### **Mental Welfare Commission for Scotland (Fee Payable to Designated Medical Practitioners) (Scotland) Regulations 2005 (SSI 2005/412)**

### **Mental Health (Care and Treatment) (Scotland) Act 2003 (Code of Practice) Order 2005 (SSI 2005/417)**

**The Convener:** Agenda item 3 is our consideration under the negative procedure of the six instruments that are listed on the agenda. The Subordinate Legislation Committee had no

comment to make on the instruments, no comments have been received from any member and no motion to annul has been lodged. Are we agreed that the committee does not wish to make any recommendations on the instruments?

**Members** *indicated agreement.*

**The Convener:** I thank the minister for his appearance and also his officials for taking time out to come to the committee and sit and listen.

**Lewis Macdonald:** Thank you.

## Human Tissue (Scotland) Bill: Stage 1

14:11

**The Convener:** We move on to agenda item 4, which is the continuation of our stage 1 consideration of the Human Tissue (Scotland) Bill. This is our second opportunity to consider the bill. We will hear evidence from two witness panels. Broadly speaking, the first panel includes representatives of health bodies—they are busily taking their places at the moment.

I will read out the names of the witnesses and give their positions. When I have done so, I ask them to state briefly their interest in the bill, make a brief comment on the bill—whether they support, are neutral about or oppose it—and raise any other issues that need to be flagged up.

I suggest that we start with Dr Jeremy Metters, who is Her Majesty's inspector of anatomy. We will then move to Jan Warner, director of performance assessment and practice development with NHS Quality Improvement Scotland; Lesley Logan, regional manager for Scotland with the Scottish Transplant Co-ordinators Network; Chris Rudge, medical director of UK Transplant; Dr Oliver Blatchford, acting director of public health with NHS Argyll and Clyde; and Dr Elizabeth Robertson, associate medical director of NHS Grampian.

**Dr Jeremy Metters (Her Majesty's Inspector of Anatomy for Scotland):** I appear in this context as HM inspector of anatomy for Scotland. I am also the inspector for England and Wales, but I speak today as the inspector for Scotland. In so far as the bill deals with the Anatomy Act 1984, I very much support its provisions. I will explain why later on, if the committee wishes me to do so.

I should declare an interest in the bill. I wrote the Isaacs report, which concerned the unlawful and unconsented retention of brains on a wide scale, for the Secretary of State for Health in England.

**The Convener:** Thank you.

**Jan Warner (NHS Quality Improvement Scotland):** I am the director of performance assessment for NHS Quality Improvement Scotland. Following the publication of the report of the independent review group on retention of organs at post mortem in 2003, I was made responsible for developing standards for the management of hospital post-mortem examinations and reviewing the national health service in Scotland against those standards.

We carried out the review over the past two years and have now published a report. Our



findings confirm that hospital post-mortem examination procedures are well regulated. The issues that were raised by the public and by health professionals during the process related principally to the authorisation process; the need for a clearer understanding of the role of different people during the process of hospital post-mortem examination; further guidance on the disposal of organs and samples; and, in particular, support during bereavement, which is an issue that is handled separately. NHS QIS believes that the bill adequately covers the concerns that were raised during the course of our work.

14:15

**Lesley Logan (Scottish Transplant Co-ordinators Network):** I represent the donor transplant co-ordinators in Scotland, who work in the field. The bill will become their working document: currently, they have to obtain lack of objection from members of the public who agree to donate but will have to obtain authorisation in future. The donor transplant co-ordinators in Scotland support the bill.

**Mr Chris Rudge (UK Transplant):** I am the medical director of UK Transplant, which is the NHS organisation with UK-wide responsibility for organ donation, the allocation of organs for transplantation and the follow-up of transplant patients.

I have three areas of interest in the bill. I am delighted that it is in favour of organ donation and supportive of organ donation for transplantation, that it is supportive of organ transplantation itself, and that it is so clearly compatible with the similar legislation that is in place in England because organ transplantation is a UK-wide activity.

**Dr Oliver Blatchford (NHS Argyll and Clyde):** I represent NHS Argyll and Clyde and sit on the research ethics committee. We clearly have an interest in the research aspects of the use of human tissue in a post-mortem context. There have been several debates about the matter in various research ethics committees, especially in relation to the required level of consent. Historically, consent was always a grey area, but the ethical approach has changed during the past decade. We are broadly supportive of the consent procedure, which is the specific part that our committee considered when we reviewed the bill. We have one concern, which we can raise during the discussion.

**Dr Elizabeth Robertson (NHS Grampian):** I am associate medical director in the acute sector at NHS Grampian with responsibility for clinical governance. As such, I chair the post-mortem group, which was previously the organ retention group. The responsibility of that group is to explore

issues such as working practices and the implementation of the relevancies for the NHS locally. We welcome broadly the tenets of the bill.

**The Convener:** In the normal course of events, the witnesses would now be subjected to direct questioning from the committee, but we do not always run things exactly like that. In the past, we have taken what we call round-table evidence, and although we have not placed you around the whole table, I am aware that the Scottish Transplant Co-ordinators Network has a great many questions to ask. In those circumstances, I encourage all of you to cross-question one another and not simply to expect members to question you. Obviously, you are each more expert in each of your fields than is any member and worthwhile questions might occur to you that might not occur to us.

I will ask one or two of the members to kick off, but I encourage the witnesses, particularly Lesley Logan, to chip in with questions across the panel. I am conscious that the evidence from her group held more questions than evidence per se. I will start with those members of the committee who have indicated that they have an interest, but I invite any member of the panel to chip in with further questions of their own if they think it appropriate to do so.

**Shona Robison (Dundee East) (SNP):** My question is more for Jan Warner and Chris Rudge, but if other members of the panel want to come in, they should feel free to do so. My question is about the Human Tissue Act 2004, which established the Human Tissue Authority to monitor compliance with the act. There are no proposals for such a body to be established in Scotland although there seems to be an intention that the HTA will have a monitoring role in relation to living donation in Scotland. I suppose that what I want to know is whether NHS QIS or UK Transplant feel that that is adequate. Should we be considering an independent monitoring body for Scotland or are you happy with those arrangements? How will we be able to keep the arrangements under review to ensure that they are meeting Scotland's requirements?

**Mr Rudge:** I think that the arrangements are adequate and highly appropriate. As I said, transplantation is a UK-wide activity, and in the case of living donation the donor may live on one side of the border and the recipient on the other side. Under the terms of the 2004 act and the codes of practice for the Human Tissue Authority, we are contemplating something that goes a stage further than that, which is known as paired donation, where two relatives that are incompatible with each other can be matched up with another family whose relatives are incompatible with each other and the organs can

be swapped. That becomes appropriate under the 2004 act, and that would work far better on a UK-wide, national basis. That is the view of the profession and it is the view of UK Transplant.

**Jan Warner:** On regulation and monitoring, the standards developed by NHS QIS are unique, in that they are the first set of standards that the Health Department required the services to comply with and, in fact, they remain the only set of standards that have a mandatory element to them. On that basis, to underpin the standards, we have adopted the code of practice referred to in the 2004 act, as well as the code of practice referred to in the McLean report, and we intend to monitor performance against those standards and to identify any areas of concern, which we would share on a UK basis, because useful things can be learned on both sides of the border.

**Shona Robison:** How do you see NHS QIS and the Human Tissue Authority working together in practice? Both will have a monitoring role. Has thought been given to how communication and liaison will work?

**Jan Warner:** It has. We have a series of memoranda of agreement with a range of similar organisations in which we spell out the way in which we will work together, the information that we will share, the review of information that we will carry out together, who exactly is involved in that sharing and what we will do with the output. We obviously have a standard format, but we would arrange agreements to meet the specific requirements of the subject.

**The Convener:** Do other witnesses want to comment on that area? It is a fairly general question. I think that Lesley Logan's organisation had specific questions about part 1 of the bill and about the need to obtain permission from the procurator fiscal and how that would work. I shall now give her the opportunity to express those concerns and we shall see whether anyone else on the panel wants to say something about that area.

**Lesley Logan:** Essentially, the co-ordinators' concern was about the fact that they work alone, in the night, in hospitals spread around Scotland and in isolation, and we have never had to obtain written consent from the procurator fiscal before. Verbal consent over the telephone, given either to the donor co-ordinator or to one of the clinicians—usually an intensive care clinician—has been sufficient. A lot of the comments from the transplant co-ordinators network are about operational issues. Having subsequently spoken to various people, I think that there are workable solutions. We obviously keep donor records quite separate from medical records, in safe environments, and we want to know that we can close those records within a reasonable time.

Therefore, we hope that obtaining written consent from the procurator fiscal will be done in a timely fashion.

**Dr Jean Turner (Strathkelvin and Bearsden)**

**(Ind):** I think that consent was normally obtained verbally and now it will have to be obtained in writing. How will people physically go about that and how quickly will they be able to obtain it? Is there a time limit on verbal consent being followed up with written consent?

**Lesley Logan:** We are assuming that the consent from the procurator fiscal will be faxed to the donor hospital, to the consultants, clinicians and intensivists in charge of the patient and the donor co-ordinator. That fax will then be followed up with a letter. I think that the explanatory notes to the bill say that that should be done within a reasonable timescale. Our question is, "What is a reasonable timescale?" We would have preferred to err on the side of having everything signed, sealed and organised within two weeks to a month, rather than within six months, which would make the process seem never-ending.

**The Convener:** As no other panel member wishes to comment, I invite Nanette Milne to ask her questions on part 1 of the bill.

**Mrs Nanette Milne (North East Scotland)**

**(Con):** I have a few questions on authorisation, which arise from Dr Robertson's submission for NHS Grampian. In relation to situations in which a donor has donated a specific organ, there is an issue about whether family members would be able to give permission for other organs to be used in transplantation. Is further legislative clarification needed on that?

**Dr Robertson:** The documentation was ambiguous on that point. If permission had been given for the use of only one organ, it would be left hanging whether the individual wished to donate just that one organ or whether the rest of their organs could be used. There was scope for more clarity on that.

**Mrs Milne:** Do any other members of the panel have comments on that?

**Lesley Logan:** In obtaining lack of objection, as we do at the moment—in future, we will have to obtain authorisation—donor co-ordinators spend a great deal of time, perhaps more than an hour and a half, discussing with the donor family which organs they feel they might wish to be put forward for donation. We have passed our nationally recognised forms to the Executive because they will require to be amended. In their training, donor co-ordinators are encouraged to sit down with the family and go through the list with them. That is a more sensitive way of dealing with a family when they are suffering acutely from bereavement. Although the bill might not be specific, we are

quite clear that we would be able to ascertain fully which organs and tissues would be made available for transplantation.

**Mrs Milne:** Would it be helpful for the bill to make the position clearer?

**Lesley Logan:** That would not be unhelpful.

**Mrs Milne:** My other question is about authenticating permission for transplantation that is given electronically. What further safeguards do members of the panel think could be included in the bill to ensure that a permission that is received electronically is genuine?

**Mr Rudge:** UK Transplant has responsibility for managing the organ donor register, which is the electronic record of people's wishes. We are acutely aware that although the majority of registrations on the organ donor register are done in writing, an increasing proportion of them are done electronically, through the web. At UK Transplant, a working party is studying how to make that process as robust and reliable as it can be. It would appear that the only practicable way of doing that is for us to respond in writing to every individual who registers on the organ donor register electronically to confirm the details that we believe they have given to us and to give them the opportunity to point out whether an error has been made. That will be an expensive business.

**Mike Rumbles (West Aberdeenshire and Kincardine) (LD):** The bill does not mention the organ donor register. Is that a difficulty? Should the bill mention the register?

**Mr Rudge:** The bill does not mention the register, although the explanatory notes do. May I bring up a potential difficulty that I have on that issue?

**The Convener:** That is what you are here for.

**Mr Rudge:** Section 8 of the bill says that

"A request by an adult that a part of the adult's body be used after the adult's death for transplantation"

should be

"in writing signed by the adult"

to count as authorisation, but the explanatory notes say:

"This section provides that written requests made by the adult before the coming into operation of the provisions in sections 3 and 6 should count as if they were authorisations ... This ensures that all current decisions by adults to carry a donor card or register on the NHS organ donor register will count as authorisations".

The bill states that the written authorisation must be signed, while the explanatory notes imply that registration on the organ donor register is enough, but, at present, people who register electronically

do not sign. There is a disparity between the explanatory notes and the bill.

On the specific question of whether it would be helpful if the organ donor register was mentioned in the bill, I believe that it would be. It would be helpful to have an absolutely clear and explicit statement that an individual who has appropriately put their name on the organ donor register has thereby given authorisation.

14:30

**Mike Rumbles:** That is helpful. I asked the Executive officials about that last week, but they did not think that such a measure was necessary. However, I agree with you that it would be helpful.

I also asked the officials why section 8 is in the bill, given that section 6 states:

"An adult may authorise the removal and use of a part of the adult's body".

That is clear, but section 8 seems to duplicate it. Do you have any thoughts on that?

**Mr Rudge:** One of the issues that we have had in the past has been the status of the 12.6 million names that are on the organ donor register. Section 8, particularly if it specified the organ donor register as being an appropriate method by which authorisation has been given in the past, would make those 12.6 million names valid into the future and would carry on the validity of the organ donor register.

**Lesley Logan:** It is worth noting that 25 per cent of Scots are registered on the organ donor register, which is the highest percentage in the UK.

**Mr Rudge:** Some codes of practice state specifically that the organ donor register should be consulted whenever a patient is in a situation in which organ donation is a possibility. However, that is not in the legislation, so it is not a legal requirement. I am sorry, but I do not understand the system terribly well, so I am not sure whether codes of practice will be developed subsequently to go along with the act or whether the act will exist only in its own right. If the act exists in its own right, some statement that it is good practice—although probably not mandatory—to consult the organ donor register would be helpful.

**The Convener:** There are bound to be subsequent regulations before the measures come into force, so we can keep an eye on that aspect and follow it through.

**Kate Maclean (Dundee West) (Lab):** What is the panel's opinion of the provision under which if a mature child or adult leaves no record of their wishes, a hierarchy of relatives can be consulted. Lesley Logan probably feels a bit picked on, but I

would like to hear what she has to say about that, because, as she said, she works in the field and the bill will be a working document for her. All the submissions that we have received so far generally welcome the fact that a hierarchical structure of relatives will be on record, but her submission mentions the difference between the hierarchical structure in Scotland and that in England. I would like her comments on that.

For clarification, Lesley, will you say what happens at present when a person leaves no authorisation? How is authorisation obtained from relatives or next of kin? I always assumed that whoever I put down as my next of kin when I go into hospital or on my passport would be consulted about what would happen if I died.

**Lesley Logan:** Potential donors end up in that situation generally because of a traumatic event, such as an intracranial haemorrhage or other such bleed in the head due to a road traffic accident, for example. Stereotypically—although I hesitate to use that word—the donor co-ordinator will come across all the relatives who have descended on the intensive care unit after receiving the call, asking them to come quickly, from the next of kin—the dad, perhaps, or a brother or sister. Up to 15 relatives and friends might be present when the donor co-ordinator arrives. Current practice is that we try to ascertain from that sea of faces—most of them will be crying and very upset—which people are, as it were, the most important. Having ascertained who is the spouse or son or whatever, we try to encourage those who are peripheral to our conversation to go away and have a cup of coffee or something. In that way, we can generally reduce the number of people in the room before we have the conversation.

We know that, of those families who have discussed the issue prior to such a terrible time, about 90 per cent support organ donation. It is almost unheard of for people to go against the wishes of a loved one who is known to be on the organ donor register. As a matter of routine, donor co-ordinators in Scotland check the register either prior to or at some point during the process of talking to the family.

In some situations, there might be dissent among the family, for example with the father saying no and the mother saying yes. The process takes so long because the co-ordinator must then sit down and discuss with the family what sort of person their loved one was, whether the person was generous and so on. If, say, the loved one was a teenager whose wishes are unknown, we might ask whether the issue could have been discussed with any friends. Generally speaking, I would say that a conclusion eventually emerges from such situations.

Families might consent for only some organs to be transplanted. That is a matter of individual choice; the donor co-ordinator's job is to help the family to reach the decision—either yes or no—that is right for them. Following that, the co-ordinator will be involved in organising the process of retrieval. A team of specialist doctors and nurses retrieve the organs, which are then sent to the part of the country in which the transplantation is to take place.

By providing for a slightly different process of authorisation, the bill will give us the ability to have a slightly different conversation with the family. The bill will also strengthen the weight that is attached to the loved one's wishes, with which we would always want to comply. However, we still need to iron out in our heads how far we would want to be able to take that.

Situations in which one next of kin says yes and another says no will still be difficult for two reasons. First, the family is important to us because, without their support, we could miss important issues in the family history of the potential donor. We want to ensure that transplants are as safe as possible, so we want the family's support. Secondly, we do not want to be put in the position of saying, "Your loved one wanted to donate their organs and tissues so, although it goes against your wishes at this terrible time, we will go ahead anyway." Sensitive handling is required because the greater good will come from increasing the number of people who might be saved by the gift of life that a transplant offers, so we do not want the adverse publicity that might come from removing organs without a family's support. For those reasons, the process of discussing with the family—however long that discussion takes—will still be required.

**Kate Maclean:** What I am trying to get at, I guess, is that the bill provides for a hierarchy of relatives, whereas families are different, or disparate, and include estranged relatives. The hierarchy of relatives that is written into the bill might be okay for some people, but it is certainly not the hierarchy that I or others would choose. Ultimately, might not providing such a hierarchy make things more difficult, given that people might then claim that their place in the hierarchy gives them more rights over the decision than another person has? Will the bill actually make things easier?

**Lesley Logan:** We think that it will make things easier. There are other considerations that we have not touched on, such as those around cultural and ethical differences. For example, should we speak to the gentleman in a Muslim family even though the lady might be the next of kin? We train our co-ordinators to be able to deal with a range of issues.

All that the proposal does is to give us a framework that we can work within. When we enter that room of 15 people, it will allow us to say, "I want to speak to the husband and wife and then I want to speak to the children." Sometimes, you have to split families into different rooms and speak to people individually before bringing them together for a consensus.

**Kate Maclean:** Who in the hierarchy would have the first decision, a mother or a father?

**Lesley Logan:** We do not approach it in such a black-and-white manner. The decision that is made has to be the right one for both of them. Sometimes, that involves a compromise for one or other of them. Generally, we ask questions about the child such as what they were like, what things they were involved in, whether they were scared of needles and whether they wanted to donate blood or bone marrow, which they might have wanted to do if there was a child at school with leukaemia. Those questions enable us to develop a picture of the child and, during that process, most families enter into the debate and reach a natural conclusion.

**Dr Metters:** Mike Rumbles commented on the need for sections 6 and 8. I would suggest that they are needed. Section 8, in particular, legitimises consent that is given before the act comes into effect. Reading that section, I immediately looked at part 5 of the bill, which amends the Anatomy Act 1984, and saw that it will need a similar section if we are not going to disallow consents relating to anatomy that have been given before the date on which the new section will come into effect.

On another issue, the consent arrangements for transplantation are less rigorous than the consent arrangements for anatomical examination. That must be right, because one is for preservation of life and one is for other purposes. In that regard, the higher requirement in section 48 is entirely appropriate, when compared with the life-saving potential of the consents that are given in the transplant section.

**Mr Rudge:** I agree with Lesley Logan that it will be helpful to have a defined hierarchy in a clear legal framework. I ask for clarification of one issue. Nowhere in the bill do I see a statement that says that although the hierarchy defines appropriate authorisation, it does not carry with it an obligation that donation will follow. As Lesley Logan said, there can be some difficult family situations in which a compromise cannot be reached. The law might be quite clear that the person at the top of the hierarchy has given authorisation for donation to proceed, but the practicality of the situation might be that it would be quite wrong to proceed with donation because the rest of the family are too upset. It would be helpful if the bill explicitly

said that authorisation does not imply an obligation that donation for transplantation must follow.

**The Convener:** You are saying that simply getting one tick on your list does not mean that you should go ahead with the transplant.

**Mr Rudge:** Precisely. Normally, of course, that is what would happen, but I would like it to be made clear that, if the co-ordinator's professional view of the situation is that donation is not in the best interests of everybody—

**The Convener:** You do not want the co-ordinator to be bound by the authorisation.

**Mr Rudge:** Precisely.

**The Convener:** Dr Blatchford, you sit on an ethics committee. Do you have any comments about any of this?

**Dr Blatchford:** I agree with Her Majesty's inspector of anatomy's comment that the duty of preservation of life is the greater one. However, from the point of view of ethics, we are more interested in research and the use of tissues, so I would want to stand back from this issue.

**The Convener:** You are not involved in the human response at the point of transplant.

**Dr Blatchford:** No. I am quite comfortable with the issue of compromises that has been mentioned and the points that have been made about sensitivity and so on. However, that is not what I was here to discuss originally.

**The Convener:** Kate, as you kicked all this off, would you like to come back in at this point?

14:45

**Kate Maclean:** Just on one specific issue concerning parents. Last week, the Executive said that if two parents could not agree, a transplant would not go ahead. If somebody's parent had not seen them for X years and the parent who had care of the child authorised the donation to go ahead, why do you think that the estranged parent should be able to veto that?

**Mr Rudge:** Those would be very difficult circumstances, and the matter would have to be discussed on a case-by-case basis. Although, in principle, I agree with what you say, there may be occasions on which the greater good is served by not proceeding.

**Lesley Logan:** We have run a successful schools education programme for the past two to three years. Every secondary school in Scotland has received an information pack and co-ordinators regularly go into schools to give fifth-year pupils the facts about organ donation and transplantation. In at least three cases in Scotland, donations following a death have gone ahead

because someone was able to tell the donor coordinator what their sister or father wanted because of a visit to a school. That is to be encouraged.

**Mike Rumbles:** We will come on to consider the word “authorisation”, which is what this is all about. Kate Maclean talked about somebody being able to veto somebody else’s authorisation. That seems strange to me, too. The bill’s provisions are based on the wishes of the individual, not necessarily the consent of the relative. Are we not trying to find out what the wishes of the deceased person are likely to have been? The hierarchy seems sensible to me if we want somebody to give that kind of authorisation, but it does not seem right to me if somebody else further down the list can somehow veto an authorisation. That could lead to the clinicians not going ahead with a donation because somebody in the family who is lower down in the authorisation hierarchy vetoed it.

**The Convener:** Lesley Logan is the one who is on the ground, although Chris Rudge will want to come in on this issue as well. I assume that, in the circumstances that have been described, the decision would depend on how far down the hierarchy the veto was attempted. A view would be taken of the circumstances at the time and, even if almost the entire family—including a second cousin, twice removed—was feeling a bit upset about it, the donation might still go ahead.

**Lesley Logan:** Yes. The most important things are that the person has spoken to their loved ones about donation and that we know that he or she is on the organ donor register, so that we can say that it would be against their wishes for the donation not to go ahead. People do not often go against the deceased person’s wishes—it is almost unheard of.

**Mr Rudge:** I am sure that, on the vast majority of occasions, the person who is highest in the hierarchy will have the legal authority to give the authorisation, which will be followed through. Nevertheless, I am sure that Lesley and I have both been in situations in which the families have been so divided, hostile, upset, angry, disturbed and distressed that to take the patient to the operating theatre and take their organs out just has not been the right thing to do, despite the fact that legal authorisation has been obtained from the person who is at the top of the hierarchy.

**The Convener:** I think that we can now move on to a slightly different issue.

**Janis Hughes (Glasgow Rutherglen) (Lab):** The evidence from NHS Grampian talks about the fact that there is no mention in the bill of non-heart beating donation. You say that the omission may be intentional but you have expressed concerns

about it. Do you think that the wording in the bill is sufficient to allow the preservation of organs, especially for non-heart beating donations?

**Dr Robertson:** Although the phrase was expected to be a catch-all, it is not quite that and there might be exceptions. There is room for a little bit of clarification.

**Janis Hughes:** The phrase is not mentioned in the bill, but the bill does talk about the preservation of organs prior to potential harvesting.

**Dr Robertson:** It is also down to the establishment and quite specific definition of brain death. There will be situations in which an individual will not quite meet the specifications, although death is inevitable and predictable and there are opportunities for transplantation. It is a matter of clarifying things so that a decision is not bound by a terribly rigid structure that does not enable the outcome that everybody might desire.

**Janis Hughes:** Section 13 stipulates that only the “minimum steps” may be taken and that the “least invasive procedure” should be used to preserve organs. Are you saying that the section does not go far enough to cover your specific concerns?

**Dr Robertson:** There are two issues. The criteria for brain stem death are quite specific, but I wonder whether the bill is too specific. The other issue is the minimum procedures that can be put in place to enable the organs to be valuable without going against the bill’s ethos and doing something that is to the organs’ benefit but not to the individual’s benefit. Exactly what should minimum intervention look like? It is difficult to be specific about the territory—it is a matter of enabling without violating.

**Janis Hughes:** Do any other panel members want to give their views?

**The Convener:** You do not have to, but you have an opportunity to do so.

**Janis Hughes:** I ask whether they want to do so because only NHS Grampian mentioned the issue.

**Mr Rudge:** The first part of the section is the key. It begins:

“Where part of the body of a deceased person”.

The bill does not set out to define how death is diagnosed or certified, which is probably wise. There are existing professional guidelines on the diagnosis of death that are in the process of being refined. However, the bill refers to

“the body of a deceased person”.

Under the section, the preservation of organs for potential transplantation cannot carry on unless the person is declared dead, which is okay.

**Janis Hughes:** So in your view the stipulations in section 13 go far enough.

**Mr Rudge:** Yes.

**Mr Kenneth Macintosh (Eastwood) (Lab):** Is there an issue—or has there been an issue in the past—to do with whether maintaining for transplantation the organs of somebody who is dying is ethically sound? I am talking about organs being maintained for the benefit of a possible transplant rather than for the benefit of the patient.

**Dr Robertson:** That was the crux of my response.

**Mr Macintosh:** Has there not been an ethical decision that doing so is improper? Am I jumping the gun?

**Mr Rudge:** I am afraid that I cannot comment on the situation in Scotland, but the interpretation of the ethical and legal situation in England is that treating an individual while they are alive in a way that is not in their best interests purely for the purpose of transplantation would probably be illegal. The matter has not been tested in court, but that is the legal advice. However, that does not apply to section 13, which applies to a person who has died.

**The Convener:** We will have witnesses from the Law Society of Scotland's committee in the future. It would probably be useful to ask future witnesses that question.

**Dr Turner:** I want to ask about definitions. I think that NHS Grampian said that things seemed to be clear with respect to tissue and organs, but that there are perhaps other areas in which things might not be as clear. I am thinking of joints, muscles, prostheses and pacemakers. The research ethics committee of NHS Grampian commented on the status of the placenta. Will NHS Grampian comment on that?

**Dr Robertson:** Our thinking was that there is an assumption that organ tissue and tissue are something small, whereas organs are solid and defined. A joint might be quite large in magnitude and perhaps not what people think of as tissue. We wanted to ensure that what was written down captured the fact that tissue might include quite substantial tissue around a joint or organ.

**Dr Turner:** That relates also to whether there should be a record of the retaining of blocks of tissue. There was a debate about where such records should be kept.

Would any other witness like to comment on the removal of tissue?

**Jan Warner:** We have debated at great length how big a sample is, although more in relation to post-mortem examinations. Eventually, pathologists concurred that no professional

following professional guidelines would take a sample bigger than was required for a particular investigation, and an audit of the size of samples that are taken in practice identified that they are very small. We supported including tissue samples as part of the medical record and including joints as an organ of the body, the taking of which would require authorisation. That does not relate particularly to the section of the bill that we are discussing, but certainly in relation to post mortems, the evidence suggests that large pieces of tissue are not being taken, so there was less anxiety about that.

**Dr Turner:** Is everybody happy with the placenta being examined?

**Jan Warner:** That was another major point of discussion. Members of the public had very clear views on examination of the placenta. It was suggested that for the purpose of the standards, on which there have been no legal findings and which have not been tested, authorisation would not be required to examine a placenta under 26 weeks and it could form part of the examination of the mother. That was the rule of thumb that we went by.

**Dr Turner:** Do you think that the bill needs to state more specifically what we are talking about, rather than just the wider aspect of what we consider tissues and organs to be?

**Jan Warner:** That might be helpful. There is a lot of professional guidance, particularly from the Royal College of Pathologists, on the subject. One has to consider whether to cross-refer to professional guidance, which we would expect people who are qualified to do such examinations to follow—we check that they are doing so—or to include the guidance in the bill. There is a fine line in relation to how operational one allows the bill to become. If one goes down the route of being explicit, in how many other cases would one need to be far more explicit?

**Dr Turner:** The next question concerns pathologists. On the one hand they are very happy with the bill and what it is trying to do, but on the other they would be dealt with much more severely than would other medical practitioners if they were guilty of malpractice. Would anyone like to comment on penalties for not complying?

**The Convener:** Do any witnesses have concerns about the penalties?

**Dr Robertson:** We mentioned them in our submission. We said that trends were probably more important than single incidents. We should consider the motivation behind something and whether there is a trend, rather than whether, in retrospect, something on one occasion might be considered to have been inappropriate. There is a fine line there.

15:00

**Jan Warner:** My experience is that pathologists, because of what they have been through over the past 10 years, particularly in paediatric cases, would welcome the opportunity to demonstrate that they comply with up-to-date standards and guidance. They recognise that the downside to that is that there might be a penalty for not complying. However, they are in the unique position of being able to demonstrate their compliance more explicitly than other professions can. Pathologists have been through a tough time, but they recognise that it is now time to move on.

**The Convener:** That is probably the end of our consideration of part 2 of the bill. Shona Robinson has questions about part 5 for Her Majesty's inspector of anatomy, Dr Metters.

**Shona Robison:** I am concerned about authorisation for donating one's body. Currently, it requires verbal consent before two witnesses. Concerns have been expressed that the bill's proposal that only formal written authorisation can be accepted might deter some people from donating their bodies, which would reduce the number donated. Are you aware of those concerns? How do you respond to them?

**Dr Metters:** First, I am aware of the concerns. Secondly, there is currently a shortage of body donors in Scotland and throughout the UK. Obviously, anything that would reduce the number of donors would be of concern to anatomists and to medical and other health educationists. I get phone calls two or three times a week about the oral declaration. I am asked, for example, what constitutes a valid declaration before two witnesses, what is the last illness and so forth. It is difficult sometimes to know whether there has been a genuine oral declaration in front of two witnesses during the last illness.

Clarity is of absolute importance, so I agree that there must be a witness statement. However, we could then get into difficulties with people who cannot write, for whatever reason—blind people are instanced in the bill. It is a difficult area. However, the bill's proposal for a written statement by a donor and an accompanying witness statement by two independent people written at the same time would get over many of the difficulties that can arise when there is nothing in writing. Often, it is simply a case of someone saying, for example, that their granddad had made a declaration but they were not sure who else was there at the time. Such situations cause many practical difficulties for bequeathal secretaries, who must deal with requests. When they do not know what to do, they tend to ring me, which is not a particularly comfortable position to be in.

The procedure that the bill proposes would be an improvement. However, there will undoubtedly

be cases in which there is only an oral request; those would not be taken forward under the bill's proposals.

**Mike Rumbles:** The bill plans to retain the post of Her Majesty's inspector of anatomy for Scotland, but leaves open the question whether the functions are to be carried out by the Human Tissue Authority on behalf of Scottish ministers or whether a separate post is to be established in Scotland. Do you have any thoughts on that matter?

**Dr Metters:** I had thought that you might ask me that. If a separate post were established, it would be a small one. It could, of course, be combined with other official duties for which someone would be accountable to Scottish ministers. That is one option. The choice depends, to an extent, on decisions that the Human Tissue Authority may make in respect of England. A comment that I receive from all parts of Great Britain—except Northern Ireland, with which I do not deal—is that it is nice to have a single inspector covering everywhere from Plymouth to Aberdeen, to take two extremes. They may not like some of my decisions, but they know that those decisions will be consistent.

If the human tissue authority is to appoint a single inspector for England, the anatomists would say that there would be advantage in Scotland linking with that inspector to cover the whole United Kingdom. If, on the other hand, there are to be regional inspectors in England, the argument for having a single inspector for the whole of Scotland and part of the UK is much less strong. I can report to the committee that without a single exception anatomists would like to have a single inspector for the whole UK.

**The Convener:** Is there anything that the witnesses wish to discuss that has not already been raised? Are there any aspects of the bill that need more scrutiny or any points about which you would like us, on your behalf, to ask future witnesses?

**Mr Rudge:** There is a minor detail that could usefully be clarified. Throughout the bill, it is made clear that authorisation for organ donation can be withdrawn at any time. However, as the process of donation gets nearer and nearer, things are also happening to the potential recipient of an organ in another hospital. There must come a time when withdrawal of authorisation for organ removal would have potentially catastrophic or lethal consequences for the recipient. Although I absolutely support the concept that authorisation can be withdrawn, there has to be a practical limit.

**The Convener:** A point of no return.

**Mr Rudge:** Yes. I am not sure how that could best be put into practice, but it would be helpful to



think about it. I do not know whether Lesley Logan has anything to add to that. There have been cases in the United Kingdom in which we have got awfully close to causing the death of a recipient in one part of the country because consent has been withdrawn in another part of the country.

**Lesley Logan:** The current advice to families about withdrawal of lack of objection is that they can withdraw at any time until their loved one goes to theatre—that is currently the end point. When that happens there is no going back, because by that time there may be a recipient in theatre—or being prepared to go to theatre—elsewhere in the country.

**Mr Rudge:** The bill says that authorisation can be withdrawn at any time.

**The Convener:** You have raised an important issue.

Dr Robertson, do you want to raise a different issue?

**Dr Robertson:** Yes. Historically, the communication of results of post mortems and the working practices and guidelines around that have sometimes been a problem that has led to misinformation and misunderstanding. We wonder whether the good practice guidance could highlight the mechanism for passing on and discussing post-mortem findings.

**Jan Warner:** On that point, the standards contain a fairly detailed section on passing on of information not just to relatives and remaining family and friends but to general practitioners and other people who have been involved in caring for the patient, so it may be that the foundation for the guidance is already in place.

**Dr Blatchford:** Our written submission is perhaps not as clear as it might have been, so I will sketch out the reason why we raised a slight concern about the use of ante-mortem samples in a post-mortem context. When a person dies, it is clear that consent is needed to do something with their tissues or organs. Likewise, if somebody goes into hospital and, in the course of another procedure, some tissue is taken for a research purpose, it is clear that they need to give consent.

However, what happens if somebody goes into hospital, a blood sample or some tissue is taken and stored for whatever reason—labs store tissue as part of their routine procedures—and then the person dies and a researcher wants access to the ante-mortem sample because they want to investigate some aspect of the death as part of their research programme? That piece of tissue or blood sample could not be considered to be a post-mortem sample because it was taken ante mortem; it is clearly in a grey zone. We would appreciate there being in the bill a mechanism that

would help to shed some light on the status of such samples. Our ethics committee has faced that issue a few times and there have been proposals for the use of stored ante-mortem samples in a post-mortem context. That is an anomaly that I thought I would draw to the committee's attention and explain our thinking on it.

**Mr Macintosh:** I have a question for Mr Rudge. Do you keep a register of anyone who refuses permission or do you keep information about people who were on the register but have withdrawn from it?

**Mr Rudge:** The organ donor register is the only register of people who wish their organs to be used after their deaths. We have no register for people who want to object. If someone registers their name on the organ donor register and then withdraws, we know about that. Does that answer your question?

**Mr Macintosh:** I think so.

**Dr Metters:** I have three quick points that probably should have been in the evidence. The first is about the proposals that a body donor should be in charge of what happens to their body; they are not at the moment. That is very important because it is all part of improving the autonomy of the individual in deciding what happens to his or her body, such as whether photographs can be taken or parts kept and so on. Secondly, the bill will liberate the unhelpful restriction on training of surgeons in joint surgery, which was inadvertently written into the 1984 act. Thirdly, the bill will put imported bodies—fortunately there have not been any so far—in the same category and not outwith the law. Those are three very important features of the bill.

**The Convener:** I do not want the members of the panel to suddenly decide that they have questions to ask after an hour of discussion; we have another panel waiting in the wings. We should be as brief as possible.

**Jan Warner:** In response to Mr Macintosh I would say that there is a real dilemma. In the majority of cases we can get authorisation, particularly in post-mortem cases. Occasionally, however, we cannot and we have a small group of people who are in regular contact with us and are extremely concerned that a hospital might see a need for a post mortem that they are against and they find it difficult to know how to make their wishes known. They are concerned that the hospital might not know who their solicitor is or that it might not be able to get that information. The service has to address such issues.

My final point is on disposal, which also came up frequently in the course of our reviews. At the moment, disposal has to be done respectfully and

lawfully. If the hospital goes with the letter of the law, that means a yellow clinical-waste bag and an incinerator, but the majority of people would not find that particularly respectful—

**The Convener:** Absolutely.

**Jan Warner:** Indeed, it might not be lawful, depending on how one views such matters. Section 2 of the bill does not refer particularly to disposal and, on re-reading it, we wondered whether there would be merit in having it refer to other documents that do refer to disposal. That is an issue of concern, particularly in respect of body parts or tissue samples where things can get quite complicated.

**Lesley Logan:** The process of tissue donation is, in some respects, quite separate from the process of solid-organ donation. Some people cannot donate solid organs and go on to donate tissue only. For them, the consent or authorisation process will be quite different. Before they leave hospital, a family will be asked for a suitable time and a telephone number. The tissue co-ordinators then get a telephone consent, which is taped. There is a lot in the bill about having witnesses, although the donor might be at home by himself or herself; for example, it might be a man who has lost his wife. There would be no provision for witnesses in such a situation. That part of the bill needs to be teased out further.

15:15

**The Convener:** It will take a minute or two for us to swap panels. I thank all the witnesses for coming along, particularly Dr Metters for coming up from London.

I welcome the new panel: Murdoch MacTaggart is vice-president of the Procurators Fiscal Society; Professor Anthony Busuttil, is a member of the Human Tissue (Scotland) Bill working party of the Law Society of Scotland and, if I recall from my previous existence as an advocate, a pathologist; Dr Jim Rodger is head of medical advisory services of the Medical and Dental Defence Union of Scotland; and Dr Calum MacKellar is director of research of the Scottish Council on Human Bioethics. I will do the same run through that I did with the first panel, and ask each of the four witnesses to state their interest in the bill and to comment briefly on it, indicating their support or otherwise, or indicating particular areas about which they have concerns.

**Murdoch MacTaggart (Procurators Fiscal Society):** The Procurators Fiscal Society's interest is that procurators fiscal should have primacy in the investigation of sudden and unexpected deaths. The society welcomes the bill's acknowledgement of that primacy, and its clarification of roles and responsibilities. The bill

appears to reflect existing good practice in terms of organ donation.

**Professor Anthony Busuttil (Law Society of Scotland):** We welcome the bill, which is clear and comprehensive. We have questions about one or two aspects of the bill and perhaps one or two possible omissions, but generally it is an excellent bill.

**Dr Jim Rodger (Medical and Dental Defence Union of Scotland):** I speak on behalf of a membership organisation that exists to give advice to doctors, so we do not have a position, other than to reflect what is in the bill. However, from our point of view the bill is welcome. It consolidates matters, which makes it easier for us to interpret cases for members. My only concerns are about the bill's legal-offence ramifications, to which we will come back in due course; to some extent they seem to override the General Medical Council.

**Dr Calum MacKellar (Scottish Council on Human Bioethics):** I am the director of research for the Scottish Council on Human Bioethics, which is a charity that was set up in 1997 to follow what is happening in Scotland. I should also mention that I am a member of the Lothian research ethics committee and a lay member of the European Union ethics panel in Brussels, and I was the successor to the secretary to the working party on transplantation of the Council of Europe in Strasbourg for a number of years. Globally, we are quite happy with the bill, but there are a few serious concerns, especially related to section 7, to which I will come back later.

**Mrs Milne:** The bill proposes that an adult can give authorisation for the use of body parts for organ donation and transplantation "in writing" and "verbally in the presence of ... witnesses".

Although the Law Society of Scotland agrees with that provision, it believes that

"where the authorisation has been expressed verbally in the presence of two witnesses it should be committed to writing at the earliest"

possible "opportunity", and that such authorisations should be

"dated and notified to the ... GP either by the adult or by the hospital in which the adult is present."

Do you have any views on those comments?

**Professor Busuttil:** That question is probably addressed to me. The written word is probably much more useful than simply having a witnessed verbal authorisation. In any case, at some stage, all expressed wishes with regard to donations should be written down. Who should be the recipient of that written document? I think that it should be the GP, who will after all be the first port of call for the transplant co-ordinator from the

hospital. If the GP does not know about it, who should? Authorisations should be written down and sent to the GP, who should, if possible, also be made aware of any revision of an authorisation. In short, any authorisation that is verbally expressed should also be written down. There should also be a repository for authorisations with a point of contact for the hospital's transplant co-ordinator.

**The Convener:** I am interested in those comments. As you were speaking, it struck me that, on the back of the bill, there will have to be a huge campaign to get people to write down their consents and to ensure that they are lodged in a place where others can find them. Do you share that view? After all, if that does not happen, people's consents might well lie in their chests of drawers and other such places.

**Professor Busuttil:** The bill's preamble says that education is an aspect of the proposed legislation; however, with respect, I do not think that it says anything about or fulfils any objective in that regard. Education of prospective donors should be part and parcel of it.

**The Convener:** Jean, I should have come to you first—I know that you want to ask about the role of the procurator fiscal.

**Dr Turner:** On verbal consent, the Law Society of Scotland felt that a request would need to be made in writing before organs could be donated, which would require guidance. Moreover, the Law Society says that the

"functions of the procurator fiscal in providing consent to removal of a part of a body should be specified".

Am I right in thinking that that is not current practice?

**Murdoch MacTaggart:** The procurator fiscal would not give consent in place of a relative. Such consent is essentially given from their viewpoint, although a death might be reportable to a fiscal and a body might be required for a post mortem as part of the fiscal's functions. Transplant surgeons who know that a person wishes to donate organs will seek to take those organs and will contact the fiscal before any post-mortem examination takes place to ask for authority to do so. In that respect, we are simply talking about the fiscal's authority; that neither replaces—nor purports to replace—the family's consent.

**Dr Rodger:** As a GP of 20 years' experience, I believe that we must be extremely cautious and clear about whether the GP record is the correct place to retain such information. In the great days in the future when electronic health records are universally available to the appropriate people, it might be useful to place that information there. However, given that at the moment GP records

are bundles of bits of paper with multiple filings, it is perhaps rash to assume that they are the best place to store that information. Such a matter will need to be discussed with GPs. There are all kinds of material—such as, for example, living wills—that should be lodged where people can access them. As a general practitioner, it is difficult for me simply to accept that the GP is the best place for that.

**The Convener:** The immediate reaction of many people might be that a solicitor would be the best person with whom to lodge such documents. In the circumstances, I do not know whether that would work as well. People tend to think of writing their will and perhaps part of their will might be the stipulation. That would rest with a solicitor and not necessarily with a GP. The point that you raise is interesting; we need to clarify that.

**Mike Rumbles:** What about the NHS organ donor register? Is not that the natural place to lodge the information?

**Professor Busuttil:** I accept that entirely.

**The Convener:** The bill does not require that.

**Mike Rumbles:** I have made that point last week and this week. Is it right for the bill to mention that?

**Professor Busuttil:** I had intended to make that point later. The register and the human tissue bank, which is now on a national footing in Scotland, must be part and parcel of the regulation and so on under the bill, but they are not.

**Dr Turner:** I will perhaps ask the obvious. If something happens at night and general practitioners have opted out of out-of-hours provision, how on earth might records be obtained? It is sometimes difficult to obtain records. In the past, a GP could be phoned for the information, because they would still be on call, despite having a deputy. Will Dr Rodger comment on that problem?

**Dr Rodger:** We would have precisely the same problem if the information was lodged in a solicitor's office.

**The Convener:** Absolutely.

**Dr Rodger:** Ready access to the information would not be available. In the not-too-distant future, when proper electronic records are kept, they will be the ideal. They will be available to hospital staff and to anybody who needs access. However, such a system is a long way away.

The other major problem with keeping information in general practitioners' records is whether it is up to date. To shove away consent in a GP's record does not mean that it is tested frequently—it may be 20 years out of date.

**The Convener:** The same can be said of any register, whether it is written or electronic. It can be assumed only that the record is an accurate reflection, unless information to show otherwise is provided.

**Professor Busuttil:** The working party discussed the issue and all the points that have been rehearsed. It is sometimes difficult for the organ transplant co-ordinator to find out who a patient's GP is. It is impossible to find out who a solicitor is in the middle of the night or at the weekend.

**The Convener:** Absolutely.

**Professor Busuttil:** We came down on the side of the best possible option and thought that electronic records might solve the problem in the future. More GPs are moving promptly in that direction.

**Janis Hughes:** My question is to the Scottish Council on Human Bioethics, which has given the committee a lengthy paper that details several objections to the bill. You are concerned about whether it is ethical for a person to give authorisation if the individual who has died has left no indication of their wishes. You have explained clearly why you are concerned. I am interested in other panel members' views, but I ask the council's representative to comment on the suggestion in your submission that European legislation could be infringed, and on how that ties in with the opt-out system that is used in Spain. How does that manage not to infringe European legislation when you say that the bill would?

**Dr MacKellar:** Thank you for that question. The European convention on human rights is regulated by the European Court of Human Rights in Strasbourg. That convention is the main piece of legislation that the court considers, but judges of the court are allowed to inspire themselves with other European legislation that has been drafted by the Council of Europe, and by recommendations by the Council of Europe's Committee of Ministers. Another important piece of biomedicine legislation at the Council of Europe is the European convention on human rights and biomedicine, which states that, prior to any health intervention, there should be informed consent.

15:30

The problem arises with presumed consent. There are a number of countries where presumed consent exists—about two-thirds of European countries—but the system is not really advertised and the people in those countries do not know about the system. If you go to France and ask anybody in the street what system they have, most people will say that they do not know that

presumed consent exists in France. I quite often go to France and I ask my friends that question; some are concerned—even horrified—that presumed consent exists and that the state can legally and officially take organs from them once they are deceased. The problem is that there is no "informed" part in the informed-consent procedure in France. The system exists, but most people do not know about it. In Spain, things are different, because many people in Spain speak about transplantation. It is spoken about in the churches and a lot more in the media.

Such a procedure can be taken to the European Court of Human Rights if it can be shown that there was no informed consent. I spoke to the former head of the French national ethics consultative committee just a few weeks ago about the problem of presumed consent in France, and he eventually acknowledged that what was taking place in France was not ethical. That is where the problem lies.

**Janis Hughes:** Your evidence actually goes so far as to say that

"the proposed bill seems to have been drafted with the aim of increasing the supply of organs for transplantation, or of human material for education, training, research or audit at the expense of ... ethical principles".

I do not know whether you heard the previous evidence that we had from the transplant co-ordinators representative. She detailed quite specifically the procedure that transplant co-ordinators go through when someone is in intensive care, or has already died as the result of an accident, before any decision is taken. She told us how long they spend with loved ones, friends and relatives, and she described the procedure that they go through. Are you saying that, if all that time is spent with a relative, detailing what their loved one would have wanted in life based on their views on various things, it is still not ethical for a relative to give authorisation for organs or tissues to be used?

**Dr MacKellar:** It depends on the circumstances. We have also been hearing of the problem that arises when children have died or where people have lost the capacity to make a decision before their death. In such cases, it is important to include relatives to try to find out what the different possibilities would be. There is also a place for relatives to be asked if they know what their loved ones wanted. The problem arises when the relatives do not know what their loved ones wanted, and what would be ethical in that case is not to proceed with the transplantation.

In our evidence, we gave the example of elections in Scotland. People in Scotland are entitled not to vote, or they are entitled to vote but not put any crosses anywhere on the piece of paper. That is something that is accepted in

Scotland; we are not forced to vote. In some countries around the world, people are forced to vote, but in Scotland we are not. It would be wrong for an electoral officer to go and ask a person's relatives after the election which party that person would have wanted to vote for. That would not be acceptable, and it is exactly the same for transplantation. It would not be acceptable after a person's death to go and ask relatives what that person would have wanted.

What we should do—it is something that we would very much encourage and something that is happening in Scotland right now—is encourage people before they die to make a decision about transplantation. That is something that the Scottish Executive has already promoted in high schools, and figures are going up. In 1995, only 2.25 million people were on the organ donor register; in 2005, there are 12 million—six times as many as in 1995, and that has happened in only 10 years.

We should be encouraging people to think about these issues and to put their names on a donor register so that we can be sure that that is what they want. When people leave the decision to their relatives, it might not reflect what they really wanted. That was the problem with Alder Hey—without consulting the families, medical doctors assumed what was best for medical research, but that is not ethical. Perhaps it was ethical a few years ago, but it is no longer ethical. That is why we are concerned about section 7 of the bill. I am sorry that I am going on a bit—I am getting carried away.

**Janis Hughes:** I do not disagree that the number of people wanting to offer organs prior to their death is increasing. However, the number of people who need organs is also increasing. You draw a sad analogy with the electoral system in this country because, after all, we are dealing with people's lives in the bill. We are also talking about potentially saving lives.

**Mike Rumbles:** We are talking about authorisation, not consent. The bill makes it clear that when we do not know what the intentions of the dead person were, there is a hierarchy of people in charge of the body—to put it bluntly, the next person down the line is legally allowed to authorise consent. The position taken in the bill is that there is no presumed consent. In paragraph 17 of your submission—and you have repeated this verbally—you say that such power of authorisation

“may be open to a legal challenge at the European Court of Human Rights under the European Convention of Human Rights”

and you mention various articles, such as article 8, on the

“Right to respect for private and family life”.

Who would take that course? Surely that is a red herring? If there is a clear legal hierarchy, as we discussed earlier, and someone is legally entitled to authorise the donation of organs, who would then make the legal challenge and on what basis?

**Dr MacKellar:** Article 5 of the European convention on health and biomedicine states:

“An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.”

**Mike Rumbles:** That refers to a living person.

**Dr MacKellar:** Yes. In the spirit of that European convention on health and biomedicine, it also refers to the donation of organs after death.

**Mike Rumbles:** But one could also say that in the spirit of that convention it is the person who is in charge of the body who gives consent.

**Dr MacKellar:** That would have to go to the European Court of Human Rights to be decided. We did not say that such a challenge would be successful in the European Court of Human Rights, but that the law would be open to a challenge.

**Mike Rumbles:** I would still like to know who would make such a challenge.

**Dr MacKellar:** We could.

**Kate Maclean:** Some of my question has already been answered. It would be highly unlikely that a relative would give consent for an organ to be released for donation without having some idea that that is what the dead person would want. It must be difficult to allow a relative's organ to be released for donation when you have been recently bereaved. It is difficult to think of the body of the person that you loved being cut up and having its organs taken out. I cannot believe it likely that anybody would take that decision flippantly or maliciously. I imagine that people would err on the side of caution rather than saying, “Take any organs you want.” Are you not suggesting circumstances that will not arise? What circumstances can you imagine in which somebody would act maliciously or flippantly? I just cannot see it.

**Dr MacKellar:** I agree entirely. I do not think that that is very likely. Unlikely cases do occur, however, and the law should be careful enough also to address those unlikely cases, even though there might be only a very small number of them.

There is a problem with the manner in which relatives make their decisions—you are right to say that it is very difficult for them to do so—and it would be interesting to find out how they make their decisions. Paragraph 10 of the policy memorandum that was distributed to us states:

“For reasons which are not entirely clear, but which may be related to the effect of issues surrounding retention of

organs at post-mortem examination, in ... Scotland, the relatives' refusal rate where the deceased's wishes are not known has risen from just over 30% in the early 1990s to around 49% now."

Relatives are trying to make a difficult decision, and they can sometimes be at a loss as to how to do that. We can see that in the variation rates of what people do and do not consent to. We in the Scottish Council on Human Bioethics are concerned that anything done to the body should reflect the wishes of the deceased person. If there are some cases where the deceased person's wishes to do nothing are not respected, there would be ethical problems.

**The Convener:** Surely this is the point of the bill. When we talk about the hierarchy, we use the words "consent" and "authorisation". In truth, is the exploration with that hierarchy not to do with what the views of the deceased person might have actually been, even if they were not written down? We perhaps ought to be careful with how we use the words "authorisation" and "consent" in this regard, when we are talking about the deceased's relatives. Surely the point is that, in the absence of any explicit instructions, it will be explored with the family what the person was like in life and how likely or otherwise it might be that they would have wished a certain decision to be made.

**Dr MacKellar:** But why did the person not give explicit consent before they died?

**The Convener:** You are assuming that, if people do not give explicit consent, it means that they are opposed. That is not necessarily the case, however.

**Dr MacKellar:** It is not necessarily the case—that is the problem.

**Dr Rodger:** I do not want to speak for the transplant co-ordinators, who spoke for themselves earlier, but I am sure that you have been made aware of the intense efforts that are made to gain knowledge of the wishes of the deceased person. That is done in a family situation. It seems extraordinary to me that a family would not at least have an appreciation of the deceased's wishes, particularly any objections to transplant. Medical and nursing professionals agonise intensely over these matters, and they explore the issues fully. I am aware that there might be a lack of knowledge, but that is their professional role. Ethics, as an institution, changes: our ethical values change over the years. That is what society is about. It sets new ethical values and changes existing ones. Simply calling something unethical yesterday does not make it unethical tomorrow.

**The Convener:** I wish to explore that. I will bring Professor Busuttil back in but, before I do so, I would like to ask you, Dr MacKellar, if we can turn

the situation on its head. You speak about a lack of consent and the possibility of the family making a decision when there is no explicit consent. As we have already heard this afternoon, if the family is in considerable distress, notwithstanding explicit consent having been given, the likelihood is that the donation and the transplant will not go ahead, because it would not be appropriate given that family's distress. In those circumstances where there is explicit written consent, would you insist that, notwithstanding the distress to the relatives, the transplant must go ahead?

**Dr MacKellar:** That is what the bill suggests.

15:45

**The Convener:** Do you think that that is the right position to take?

**Dr MacKellar:** We are discussing what to prioritise: the wishes of the deceased person or those of the relatives. It is the view of the Scottish Council on Human Bioethics that the wishes of the deceased person should take priority over those of the relatives.

**The Convener:** So you think that it would be proper, notwithstanding the extraordinary distress to the family, to put the wishes of the deceased person before those of the family. Some committee members might think that that is the right thing to do, but we have heard evidence that it is highly unlikely that that would happen in practice. You are saying that it should happen, notwithstanding the distress that that would cause.

**Dr MacKellar:** The situation that you describe is highly unlikely, because many families would want the wishes of the deceased person to be respected. However, in the small number of cases that we are talking about, we say that the wishes of the deceased person should be put first.

**The Convener:** Interesting.

**Professor Busuttil:** The word "authorisation" is important—we are happy that it was used rather than the word "consent", because people in such situations authorise; they do not consent.

**The Convener:** We heard earlier that consent could be withdrawn at any point. There was a brief discussion of what might be regarded as a point of no return—the point at which the recipient patient has been prepped beyond safety. It was argued that, in those circumstances, there should not be an ability to withdraw consent. Will you comment on that? Do those who are here in a legal capacity agree with that? Should the bill state explicitly that consent cannot be withdrawn beyond a certain point?

**Dr Rodger:** I listened to that discussion, during which it became clear to me that the decision on

that should be for the transplant team. There will be a stage at which the recipient is beyond recovery. The matter is the responsibility of the team that looks after the recipient. Once the decision has been made to donate, the most important person is the one who is receiving the organs. Therefore, the principal aim must be to keep the recipient alive and in the best condition to receive the organs. The decision is a technical one that can be made only by the transplant team—only that team can decide when they need to move within the next 20 minutes or half an hour if the recipient is to be kept alive.

**The Convener:** So you want at least an acknowledgement that consent could not be withdrawn right up until the last gasp.

**Dr Rodger:** Absolutely—if that happened, that would be extremely unfair.

**Mike Rumbles:** I think that there is a confusion here. Correct me if I am wrong, but my reading of section 6 is that an adult can withdraw consent in writing. If I carry a donor card, I have authorised such procedures, but if I change my mind, I can withdraw that authorisation in writing. However, in section 7, which is about authorisation by the adult's nearest relative, I cannot see such a provision.

**The Convener:** It might be worth exploring whether relatives can withdraw consent.

**Mike Rumbles:** That is what we are discussing, but it is not in the bill.

**The Convener:** We discussed the issue with the previous witnesses. We must ensure that we understand the issues. The previous panel were clearly having a discussion about the withdrawal of consent during, or at least in the early stages of, the transplant process.

**Shona Robison:** We need clarification on the issue, particularly to give back-up to those on the ground—the matter should be covered in the bill.

**The Convener:** I have another question that arises out of the evidence that we heard earlier about the clarification of the legal position on the preservation of organs. We heard an explicit statement from, I think, Her Majesty's inspector of anatomy that medical intervention when somebody dies simply to ensure that organs are subsequently available for donation is a criminal matter in England. Nobody on that panel could clarify whether that is the case in Scotland. Can anybody on the present panel do so?

**Professor Busuttil:** If a dead donor is to be useful for donations, certain actions need to be taken. First, the body may have to be removed from the mortuary to a clean mortuary—the procedure cannot be done in all hospital mortuaries. Secondly, you may have to introduce

cannulae to flush the body. That must be done if the organs from a dead body—a non-beating donor—are to be useful. Some tissues, for example a joint or tendons, can be used without that, but if you are thinking of using heart valves or the pancreas, for example, you have to flush the body. However, there is no provision in the bill for that. The transportation of bodies from A to B, their manipulation and the insertion of solutions and cannulae post mortem need to be part and parcel of the bill, but they are omitted.

**The Convener:** Does anybody else want to comment on that?

**Dr Rodger:** The ethical position is quite clear: people should not be kept alive simply to be harvested.

**The Convener:** Would anybody like to comment on the differential authorisation that is required for transplant and post-mortem use of a body?

**Professor Busuttil:** The bill does not state the form of authorisation that is required for post-mortem examination with the consent of the relatives. All the health boards in Scotland have a different form. Doctors move from A to B and B to Z, and it would be anomalous if they had to learn what the form says in each hospital in which they work. Autopsy forms should be centralised and co-ordinated, bearing in mind the explicit guidelines of the Royal College of Pathologists, the bill and other nuances of Scottish practice. Co-ordination and arrangements for authorisation from the next of kin for autopsy and post-mortem examination should be part and parcel of the bill, and possibly subsequent regulations.

**The Convener:** Are there any other issues? I raised three that arose from the previous panel's evidence. Are there any specific points that you wish to raise that we have not already covered?

**Professor Busuttil:** I have one or two points. First, we get organs not only from Scotland and England, but from abroad, including from Europe and India. What trans-territorial arrangements will there be to ensure that the people we work with elsewhere follow the same ethical, moral and legal principles? There is nothing in the bill about that. We send our organs away and they send us their organs, thank you very much. If we are to receive organs, we want to be absolutely sure that they are above board, but there is nothing specifically on that in the bill.

**The Convener:** If it came to your attention that you had received an organ for transplant that had been harvested in a way that was regarded here as profoundly unethical, what would the medical practitioners do? Would they go ahead with the transplant, would they refuse or what?

**Professor Busuttil:** It depends—that is the usual answer. It depends on whether the recipient

has already been prepared. If he has no kidneys any more and you have a compatible kidney, your hands are tied behind your back—you have to insert that kidney. It is the same with a liver. Such a situation should be pre-empted before the organ is sitting on the table and the patient is in theatre waiting to receive it.

**The Convener:** What was your other point?

**Professor Busuttil:** It is on museums and teaching. What provisions are there on the use of specimens in museums? The Royal College of Surgeons of Edinburgh is full of specimens. Every pathology department up and down the country has loads of specimens. How will they be regulated? Specimens have a shelf life. What do we do with them afterwards? Will they be put in the yellow bags that were mentioned earlier, which would upset not just sensitivities but religious and ethnic beliefs? A Jewish person or a Hindu would object very strongly if organs that they had kindly donated were incinerated. We need to think about disposal and museums.

On a different point, not a fortnight passes by but somebody phones and says, "I wish to donate my body to medical science." They do not mean anatomy. They do not mean transplantation. What do we do about that? I assure you that, once a fortnight, we get a call and we do not know what to do with those people. We try to channel them to anatomy, but they say that that is not what they want. They do not want to be dissected; they want their brains or organs to be used. There is an element of that which is missed in the bill, and there is an opportunity to consider the donation of entire bodies for medical science. Can I go on?

**The Convener:** Yes.

**Professor Busuttil:** We also mention the requirements of the procurator fiscal. Where are those enshrined?

**Murdoch MacTaggart:** They are not enshrined. That is beneficial, as it means that the procurator fiscal is not restricted in his role of investigating deaths, rooting out criminality and establishing whether deaths have been caused by criminality or by the fault of another person. There is no restriction on the fiscal's ability to investigate deaths for the purpose of fatal accident inquiries, and so on. It is to everyone's advantage—to the public's advantage overall—that there is no such restriction. People who work in the medical legal field are aware of the fiscal's role, and it is to the advantage of the public in general and of the operation of the fiscal in particular that those requirements are not enshrined.

**Professor Busuttil:** However, the question is how doctors from outwith Scotland know what the fiscal wants. Is it the same thing that the coroner wants, or is it quite different? Should there be a list

of things? I accept entirely what you say; however, there must be some guidance that every doctor gets. At present, we do not have that.

**The Convener:** That takes us back to education, which you raised earlier.

**Murdoch MacTaggart:** There is a publication from the Crown Office and Procurator Fiscal Service, which provides fairly basic information. I know from my experience and that of other members of the Procurators Fiscal Society that fiscals speak to doctors, as part of their education, about the role of the fiscal. No doubt, that will continue when the bill is passed.

**Professor Busuttil:** Another problem is that there is currently a moratorium among the fiscals in terms of homicide cases—and sometimes section 1 of the Road Traffic Act 1999—on donation of organs. The relative says, "Please, please, please. It's only a head injury that this gentleman's got. I want his liver or heart donated." However, under the current Crown Office regulations, the fiscal says, "No, you cannot have that." There are obviously important aspects, such as the offence and so on; however, as we have shown in Edinburgh, there are ways in which we can get round such things, although not in every case. We are asking whether there should be some leeway in terms of that moratorium on homicide cases—

**The Convener:** I am sorry, but I do not follow what you are talking about.

**Professor Busuttil:** I am sorry. If a gentleman has died as a result of an obvious homicide, his organs cannot be donated, even if that is what his relatives wish. Often, they are excellent organs for donation.

**The Convener:** It has nothing to do with the reason for the homicide.

**Professor Busuttil:** No, it has nothing to do with the reason for the homicide. We would like that situation to be changed, as it would help the relatives substantially if they knew that their nearest and dearest who had died so horribly had—

**The Convener:** I have a vision of what defence lawyers might do in a situation in which half the remains are no longer available for hypothetical examination. That might be a legal issue.

**Professor Busuttil:** That is the reason for the moratorium; however, we would like a rethink on that.

My next question is whether blood is a tissue.

**The Convener:** Is blood a tissue? That can be added to Jean Turner's questions about definitions, for clarification.



**Professor Busuttil:** Medically speaking, blood is a tissue; therefore, it should be included in the bill. Are body fluids a tissue? Is urine or vitreous fluid a tissue? Those may be just as useful in research as any other fluid. That is perhaps missing from the bill.

The next question is on the hierarchy of authorisation. How do we cut the mustard, especially with kids? Mum says, "Yes, please"; dad says, "No, thank you."

16:00

**The Convener:** That is something that we are exploring as we go along. We have had a pretty clear indication that, if there is a serious split within the family, the presumption will be against a donation taking place.

**Professor Busuttil:** That is correct. Further, in relation to children, the bill contains no reference to the Age of Legal Capacity (Scotland) Act 1991.

**The Convener:** We had a discussion about that last week. The situation in Scotland is different to that in England.

**Professor Busuttil:** Finally, the register of donors and the human tissue bank should be mentioned in the bill. That is all that I have to say.

**The Convener:** Great.

**Dr Rodger:** I have a few points to make, one of which is about authorisation in life for a post mortem, which will be a difficult measure to implement in practice. If I went into hospital, the last thing that I would want would be to have a consent form put in front of me to say that, in the event of my death, I agreed to a post mortem.

**The Convener:** That would induce a collapse in patient confidence.

**Dr Rodger:** Absolutely. Authorisation has to be sought at some time, but it seems a highly bizarre prospect that any doctor would seek it while someone was alive.

The other matter that concerns me in my role as someone who defends doctors is the extra level of jeopardy that doctors, especially pathologists, might find themselves in under the offences that are listed in the bill. I know that submissions to the committee mentioned that the General Medical Council should deal with such professional matters, rather than getting the courts involved. You have heard the pathologists' pleas on the threat of legal as well as professional sanctions. As someone who has dealt with a number of paediatric pathologists in the years since the organ scandal came to light and who knows what they have been subjected to, I feel that we need to ensure that we do not overemphasise the legalistic aspect of the bill because there will be no

paediatric pathologists if they feel that they are at intense risk of criminal sanctions.

**Dr MacKellar:** I have just a few more points to make. The first relates to the possibility of organ trafficking. Sadly, that practice is growing because more and more people are on waiting lists around the world. Unfortunately, there is a market for organs in Europe. We wondered whether it would be possible to have an extra-territorial provision inserted in the bill so that people from Scotland who went abroad for an organ—to Moldova, Turkey, Iraq or India, for example—would face prosecution when they came back. That would deter UK citizens from going abroad to have an organ transplant in another country.

We would also like to know whether it would be possible for the Scottish Government or the Scottish Parliament to sign and ratify the European convention on human rights and biomedicine and its additional protocol on transplantation. There is already a precedent for that in that the UK Government has ratified the Hague convention on the international protection of adults for Scotland only. Indeed, Scotland is the only country in the world for which that convention has been ratified. Given that precedent for the ratification of international conventions on behalf of Scotland only, we wondered whether such ratification could be considered for the European convention on human rights and biomedicine and its additional protocol on transplantation.

**The Convener:** We would need to take that up with others.

Some members have indicated that they have questions. I discourage members from reopening matters that we have already dealt with because we have other business to move on to.

**Dr Turner:** I have a brief question for Professor Busuttil about trainee pathologists and consent. In her submission, Professor Bell, who is a consultant in neuropathology, comments on section 34(b) of the bill. She points out that trainee pathologists work under consultants and says that the fact that they work on tissue means that there could be a problem about consent. Would trainee pathologists require consent from relatives?

**Professor Busuttil:** My view is that if they are working under the supervision of a consultant—and they always will be, even though they work on their own occasionally—they are still under the umbrella of the consultant. Additional consent will not be necessary.

**Dr Turner:** They will be protected.

**Professor Busuttil:** Yes.

**Mrs Milne:** I apologise if this has been raised, convener. Could Professor Busuttil clarify the Law Society's submission in connection with those provisions in the bill concerning live donation?

**Professor Busuttil:** Yes. We want to be absolutely sure that a live donor knows exactly what is going on and that the people who are taking consent from the live donor have ensured that that person is fully informed. We are concerned that there should be no coercion or emotional blackmail. It has to be done in such a way that it is completely above board and that the authorised consent is appropriate.

**Mike Rumbles:** Shona Robison has pointed out that withdrawal of authorisation is in the bill, so I was wrong on that one.

Dr MacKellar, in section 17(1), on trafficking, the bill says:

“A person commits an offence if the person ...

(d) initiates or negotiates an arrangement involving the giving of a reward for the supply of, or for an offer to supply, any part of a human body for transplantation” —

**Dr MacKellar:** The problem is the buyers, the patients who go to India, receive an organ from organ traffickers and then return to the United Kingdom. It is not only the people providing the service but the recipients themselves who are encouraging organ trafficking by going abroad and paying large sums of money.

**Mike Rumbles:** So it would not—

**Dr MacKellar:** As I understand it, the bill only covers traffickers, but patients support organ trafficking.

**The Convener:** The analogy would be sex crimes in Thailand, and being able to pursue a Scot—

**Dr MacKellar:** There is a precedent in the United Nations conventions on extra-territorial provisions, for example on child trafficking.

**The Convener:** That just about exhausts everything, but if the witnesses think of something once they have left, they should feel free to get in touch with us again. The clerks will always accept follow-on evidence from witnesses.

16:07

*Meeting continued in private until 16:22.*

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